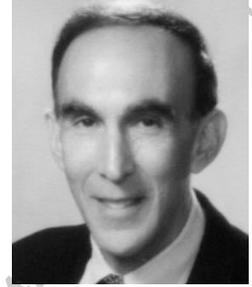


Fibromyalgia: To Diagnose or Not. Is That Still the Question?



The August 2003 issue of *The Journal* presented 3 editorials, each declaring that the diagnosis of fibromyalgia (FM) should be abandoned¹⁻³. Drs Ehrlich, Hadler, and Wolfe have no issues with the irrefutable fact that a large proportion of the population, up to 30% in some community surveys, report widespread pain. They would also agree that the great majority of these individuals have no structural disease to account for their pain. What disturbs them is the FM diagnosis itself, the label given to the subset of people with idiopathic generalized pain who often are referred to rheumatologists. Is the FM diagnosis disabling or enabling?

Diagnostic labels for syndromes manifesting subjective symptoms have always been controversial. Fifty to seventy percent of primary care visits are related to symptoms that cannot be explained by any disease⁴. Most of these symptoms are self-limited, but millions of people suffer with chronic, unexplained pain, headaches, fatigue, or bowel complaints. Each medical specialty has its own functional, somatic disorder diagnosed solely by subjective symptoms, with no definitive laboratory or structural abnormalities and prominent psychosocial risk factors (Table 1). Ehrlich contrasts FM to migraine headache, which is a "well defined condition with exacting criteria." Yet the operational criteria for FM have been as carefully crafted and validated as those for migraine. Classification criteria for each of these functional syndromes are designed to distinguish the specific syndrome from another illness with similar symptoms. The FM diagnostic criteria have been demonstrated to do just that.

Underlying the disdain for the diagnosis of these syndromes, which include FM, is the notion that such individuals exaggerate the normal strains of everyday living because they do not cope well with psychosocial stressors. Ehrlich imagines that FM does not exist in rural areas since "chronic complainers are not well tolerated" and "people get on with their lives"¹. There is a gender bias of comments such as "all manner of associated symptoms or nonsymptoms become prominent when the individual focuses on herself and

discomfort (and it is mostly women who fall into this category)"¹. Hadler suggests that the diagnostic label of FM and chronic fatigue syndrome (CFS) medicalize symptoms, thus promoting symptom magnification and excess somatic concerns². However, the single study designed to test that hypothesis found that the FM diagnostic label did not have a negative influence on clinical outcome⁵. The health status of patients with FM was compared before diagnosis (prelabeling) and after the diagnosis (postlabeling). Newly diagnosed cases reported fewer symptoms and were more satisfied with their health. No differences in health service occurred postlabeling. Hadler believes that "people choose to be patients because they have lost their wherewithal to cope." He believes that FM is a social construct that will simply go away if we stop using the diagnosis for people's misery. Editor Duncan Gordon is not surprised that some rheumatologists refuse to see patients with FM⁶. Similarly, gastroenterologists may not diagnose or treat people with irritable bowel syndrome (IBS), or neurologists may not wish to see patients with chronic headache.

Social, cultural, and political factors are important in every chronic illness. A diagnosis of FM can be exploited for personal or societal gain. It is not the diagnosis of an illness, but rather how that label is applied that results in "turning diseases into commodities"¹. This is just as prominent in disease labels such as hypertension as it is in syndrome labels such as FM. The diagnosis of hypertension resulted in increased work absenteeism when it was not accompanied by information and explanation about the meaning of high blood pressure⁷.

Ehrlich decries that the diagnosis of FM promotes support and advocacy groups that aggravate the problem¹. Certainly, if zealous, biased leaders of advocacy groups dominate for their own interests rather than "support," harm can occur. This is not unique to FM. Both Drs. Ehrlich and Hadler believe that the FM diagnosis certifies the disability complaints so rampant in FM and "turned a common symptom into a remu-

See other editorials and letters on FM in this issue.

Table 1. Functional somatic illness by specialty.

Rheumatology	Fibromyalgia
Infectious disease	Chronic fatigue syndrome
Gastroenterology	Irritable bowel syndrome
Neurology	Chronic headaches
Cardiology	Noncardiac chest pain
Urology	Interstitial cystitis, irritable bladder syndrome
Gynecology	Vulvodynia, chronic pelvic pain
Allergy	Multiple chemical sensitivity
Oral surgery	Temporomandibular joint syndrome
Physical medicine	Myofascial pain syndrome

nerative industry.” However, even in tertiary referral rheumatology centers where the most “treatment-resistant” FM patients are seen, disability claims are present in only 10% of cases⁸. This is no greater than for people with chronic neck or chronic back pain. It is not the illness label that results in such claims, but rather inaccurate illness attributions. In contrast to the term “post-traumatic FM,” the FM label, like the label of headaches, irritable bowel, and chronic fatigue syndrome, is descriptive, not implying causation. Clinicians have no business using labels such as post-traumatic FM, tension headaches, postinfectious CFS, or post-dysentery IBS unless there is evidence to support a causal connection.

Hadler’s argument that FM is simply a social construct ignores 25 years of clinical observations and research. Such a narrow-minded view of depression was common during the past century. Psychiatry has more recently applied useful and validated diagnostic classifications based solely on symptoms. This has resulted in basic research breakthroughs and important therapies. The FM diagnostic label has provided a common language for investigators to explore biologic as well as psychosocial factors and to appreciate the overlapping features of FM, CFS, migraine and muscular headaches, IBS, and depression. Forty to eighty percent of patients with FM and 60 to 90% of patients with the CFS meet criteria for IBS^{8,9}. Similar central nervous system pain perception and neuroendocrine alterations have been reported in FM, IBS, chronic headaches, and CFS^{8,9}. Techniques such as brain imaging and genetic analyses have provided a greater understanding of the interplay of physical and emotional pain so prominent in FM¹⁰.

Ehrlich says, “people labeled to have FM are given ‘a hopeless prognosis’”. Hadler believes that this “unhappy fate” of people labeled to have FM is a result of “the treatment acts, dripping with empty promises of elucidation and unproved promises of palliation, [which] are iatrogenic.” Despite these ominous remarks, most patients with FM respond well to a combination of education and treatment¹¹. The FM diagnosis has allowed clinicians to evaluate a large variety of medicinal and nonmedicinal therapies. Numerous randomized clinical trials and metaanalyses confirm that medicinal and nonmedicinal therapies are effective in FM¹¹⁻¹³ (Table 2). One report from Australia involving patients seen in a primary care prac-

Table 2. Therapies proven effective in randomized, clinical trials and/or metaanalysis in FM.

Medications
Amitriptyline
Cyclobenzaprine
Fluoxetine
Tramadol
Nonmedicinal treatments
Cognitive behavioral therapy
Exercise programs
Patient education

tice found that the majority of patients responded well to simple therapeutic approaches, and one year after the diagnosis one-quarter of the patients no longer met the criteria for FM¹². In a 3-year longitudinal, prospective study, 50% of 70 women with FM reported moderate to marked improvement¹³.

Dr. Ehrlich comments that diseases such as tuberculosis, cancer, or rheumatoid arthritis exist, whether they are diagnosed (i.e., labeled) or not. In contrast, “no one has FM until it is diagnosed.” Yet Ehrlich agrees that the “pain is real.” So what do we call it? And how do we treat it? Ehrlich declares “One cannot really treat non-diseases.” He implies that all we need to do is reassure patients that there is nothing really wrong with them, pat them on the back, and send them on their way? That may work for some people, but for most, an illness label is necessary and useful. Cassell comments, “If you do not make the diagnosis, you cannot relieve the suffering”¹⁴. The diagnosis simply implies that a person experiences something wrong. The absence of disease does not mean that a person is not ill. A sense of hopelessness follows when people are told they are “worried well.” Helplessness will result from telling someone they have FM but that there is nothing to do about it. Often people with FM have been told that they suffer from chronic bursitis, tendonitis, or structural malalignment and are treated inappropriately. Explaining that FM is not a structural injury precludes such a scenario. The FM diagnosis should halt countless referrals and costly, unnecessary medical tests.

Wolfe wants us to stop using the American College of Rheumatology (ACR) criteria for FM in the clinical setting³. But the clinical setting is exactly where classification criteria should be used. As he points out, the ACR criteria were designed as a working-case definition. As such, they work well. What concerns Wolfe is the diagnostic utility of tender points as “the essential criterion.” In the clinic and in the some 1500 reports devoted to FM in the past decade, it has been made clear that FM is not “mostly a physical illness.” The ACR FM classification criteria have not resulted in rheumatologists treating FM as “mostly a physical illness.” The efficacy of medicinal and nonmedicinal therapies in FM has been demonstrated by improvement in symptoms and function, not by a change in the number of tender points.

Operational criteria for syndromes like FM provide a foun-

dition for exploring each person's symptoms. Most people who meet classification criteria for FM, chronic headaches, or IBS never see a physician. They probably will never be given a syndrome diagnosis. However, without classification criteria clinicians will never understand why some of these people become patients. The diagnostic label allows clinicians to evaluate risk factors for illness chronicity and severity. For example, the number of painful regions, severity of fatigue, and psychosocial factors, in particular mood disturbances, correlate with FM outcome^{15,16}. Once the diagnosis of FM is established, physicians do not need to constantly be on the lookout for hidden diseases. We can then get to know the person, explore factors such as illness attributions, work issues, and psychosocial stressors. In the future, multidisciplinary therapies designed to address these individual illness risk factors will be the most successful¹⁷.

If illness labels such as FM are perceived as frameworks to approach poorly-understood chronic syndromes such as FM, healthcare professionals can establish a caring and nonconfrontational relationship, unencumbered by causal or pathologic illness attributions. A syndrome label reassures the physician and patient that there are many people with similar symptoms in the absence of disease. Patients uniformly have felt that a diagnosis and belief in their illness was beneficial. Often, this is in contrast to their health care professionals who are uncomfortable with these diagnostic labels. Ninety percent of patients with CFS reported that getting a diagnosis was the single most helpful event in the course of their illness¹⁸. However, 60% of their doctors had been reluctant to diagnose CFS because of the scientific uncertainties with the disorder. A diagnostic label signals to the patient and family that the doctor takes their problem seriously. The complaints are considered real, in contrast to what some have thought about FM. The rheumatology community should heed the plea from Wessely, "we have hopefully moved away from the tedious and repetitive rhetoric that pits the 'it's real' against the 'oh no it's not' lobbies which produce much heat and little light"¹⁹.

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